NEJM Evidence

Published June 24, 2025
NEJM Evid 2025;4(7)
DOI: 10.1056/EVIDpp2500164

PATIENT PLATFORM

What Do You Mean, I Have Heart Failure?

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In this Patient Platform, a new grandmother shares her experience receiving a new diagnosis of heart failure — and prescriptions for all the medications that came with it.

As I lay on my family doctor's examining table, the young resident palpated my abdomen, making sure there was no local tenderness remaining over my colon. I assured her I felt 100% better than I had 2 weeks earlier. All was good. I began to sit up.

"Would you mind if I listened to your heart?" she asked. "I like listening to hearts."

"Knock yourself out." I lay back down, confident that my heart, even at 67 years of age, was in excellent condition. I walked regularly, I'd never smoked, I'd never had high blood pressure, my cholesterol was good, I wasn't overweight, I rarely drank alcohol, I had wonderful family and friends, and I even meditated every morning.

She listened once. She listened twice. She listened a third time. Her head tilted, her eyes crinkled, and she got that look on her face.

"Everything okay?" I asked, tilting my own head and beginning to feel uneasy.

She said she could hear a heart murmur, but assured me everything was "likely fine, fine." She referred me downstairs for "a quick ECG."

Off I went.

It was quick, all right. But it wasn't fine. It showed a left bundle-branch block. I had no idea what that was.

Concerned, she ordered a cardiac echo. It wasn't good. The left ventricle was moderately dilated, with reduced systolic function, and the left ventricular ejection fraction was 48%. Normal, I learned, was between 55% and 70%. That's when she broke it to me — it was time for me to see a cardiologist.

Me?

In February 2024, less than 2 months since the astute resident listened to my heart, a cardiologist said I had heart failure.

Heart failure?

That doesn't sound good. What does that even mean? Did my heart actually flunk? Could I retake the test? The cardiologist was glad to know I was asymptomatic, and explained that an ejection fraction of 48% wasn't awful. "At least it's not in the thirties," he said. Little did we know that the next time it was measured, it would be down to 37%.

Was I about to die?

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I couldn't die now! One of my greatest wishes had recently come true. I was a grandmother! I'd always longed to be one, because I never knew mine. One died before I was born, and the other lived almost 2000 miles away in Jamaica. I craved the opportunity to laugh, lavish love, and be a soft port in the storm for my grandchildren. I yearned to be the grandmother that I, as a girl, had so desperately wanted and needed. In May 2023, my first granddaughter, Arlynn, arrived. It was such a thrill, as I'm the mother of three sons. In October 2023, my second granddaughter, Hailey, arrived. I was elated. Whatever heart failure was, I had two phenomenal reasons to beat it.

What were my chances? I soon received an education in the regimen of medications being used with impressive results in the treatment of heart failure. Before I left the cardiologist's office, I was given a prescription for valsartan to start ASAP. He also ordered a Persantine stress test and a cardiac MRI. I hoped I wouldn't have to wait too long for them, even though I didn't have a clue what a Persantine test was.

Driving home from the cardiologist's office, I went straight to the drugstore to pick up the valsartan. It was the first of what would eventually be five new medications: bisoprolol, Entresto [sacubitril–valsartan], spironolactone, Jardiance [empagliflozin], and atorvastatin. I wasn't really sure what all these meds would accomplish. The cardiologist had tried to explain, but most of it went over my head. What helped make the difference and helped me accept this onslaught of medications was learning that this combination — thanks to clinical trials — had improved the lives of people diagnosed with heart failure worldwide. Good to know, because I was ready to do whatever was necessary.

One month after that first cardiology appointment, I had the cardiac MRI. This result was startling, showing the reduced ejection fraction of 37%. It also confirmed, in combination with the Persantine test, that "the left ventricle had mild to moderately reduced global systolic function ... In addition, there was a paradoxical movement of the interventricular septum related to an underlying left bundle-branch block." I had no evidence of plaque buildup in the arteries of the heart, and the remainder of the investigations didn't point to a specific cause for my heart failure.

My diagnosis was: "Heart failure. Idiopathic dilated cardiomyopathy."

I had a whole new language to learn.

On top of that, every morning and evening, I had to remember to take the medications that had prolonged the lives of so many people. Adjusting to the combination of new drugs in my system wasn't easy. By week 2, I was so fatigued that I had to drag myself out of bed. I wondered if the fatigue was caused by all the new meds, or by the heart damage, or perhaps a combination of the two.

What's more, my blood pressure had always been good, but some mornings my systolic blood pressure dropped so low I was afraid I would fall. I decided that if my systolic pressure was below 90, then something was going to need to change with my medications, as I was no longer able to function normally. With the support of my cardiologist, we were able to come up with a plan to stop the beta-blocker and to adjust some of the other meds.

Today, 1 year after starting medications, my ejection fraction is up to 53%. It's almost normal! My fatigue has lessened as well. In 6 months, I'll have repeat tests and a visit with my cardiologist. If my ejection fraction remains good, and I continue to feel well, I'll graduate to seeing my cardiologist only once a year. What a relief!

I'll always be grateful for the doctors, the scientists, and the patients who participated in the clinical trials, allowing me to spend sweet times with my granddaughters. I wonder, however, if there is a role for future research to examine the outcomes of people like me who have to stop taking the beta-blocker. Should I be switched to another beta-blocker? Should I retry the same beta-blocker? If a clinical trial showed that stopping the beta-blocker could negatively affect my lifespan, I'd be willing to give it another try. After all, those granddaughters aren't going to spoil themselves.

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